## INVOLVING PATIENT AND FAMILY ADVISORY COUNCILS IN STAGES OF RESEARCH

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| Pre-Planning | • Identify meaningful research topics and potential questions.  
• Assist in prioritization of research questions.  
• Host community meeting to obtain broad input.  
• Assist in planning and facilitating a community health needs assessment | • What matters to you and other patients/family members?  
• What would you like to know?  
• What would be most meaningful to you and other patients/family members to know about this topic/condition/diagnosis/care process? |
| Planning | • Review what is known and provide ideas for gaps in knowledge from a patient/family perspective.  
• Develop a set of questions to query patients/family members about challenges and solutions.  
• Advise on protocols and questions for surveys/interviews and provide input about planning interventions and selection of outcomes.  
• Review proposal and provide feedback.  
• Write a letter of support.  
• Review materials/forms for patients and provide feedback (e.g., information about eligibility and enrollment, informed consent, surveys/questionnaires). | • What do we know now?  
• What would you like to know?  
• What would be most meaningful to you and other patients/family members to know about this topic/condition/diagnosis/care process?  
• How do different choices (e.g., treatments, medications, care processes) affect you?  
• What do you think might make patients hesitant to enroll in this study?  
• What information is critical for patients to know to decide whether or not to participate in study?  
• When is the best time to approach patients about enrolling in the study?  
• Do you have any concerns about the eligibility criteria |
<p>| Pilot | • Review results and provide feedback for changes to study.                                                                                                                                                               | Note: Questions listed above in the Planning Stage are appropriate to use in this stage.                                                                                                                                    |
| IRB Approval | Not Applicable                                                                                                                                                                                                           | Not Applicable                                                                                                                                                                                                            |</p>
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| Data Collection and Enrollment | • Receive updates about enrollment progress and advise as needed.  
• Present updates about progress of research study to health care providers and patients/families/community. | • How can we improve recruitment strategies to increase enrollment? |
| Analysis                 | • Discuss the interpretation of findings and the study’s conclusions.                     | • What do the results mean to you?  
• Do the conclusions reached by researchers make sense?  
• Is something significant being missed?  
• What will the findings mean to patients/family members?  
• Are questions left unanswered?  
• Does the study trigger additional questions to be studied? |
| Dissemination            | • Create compelling and understandable summaries of research and findings for patients/families/community.  
• Identify organizational groups/committees and community groups that should be informed about study and findings.  
• Present findings to health care providers and patients/families/community. | • Who needs to know about this study?  
• How do you find information to help you make decisions about your health care?  
• What are the best ways to inform patients/families/community?  
• How can patients/family members use these findings in shared decision-making with their health care providers? |